

August 13, 2013

National Commission on Long-Term Care
United States Senate

Dear Commissioners,

The Association of University Centers on Disabilities (AUCD) is a national non-profit organization and network of interdisciplinary programs made up of 67 University Centers for Excellence in Developmental Disabilities funded by the Administration on Intellectual and Developmental Disabilities, 43 Leadership Education in Neurodevelopmental Disabilities programs funded by the Maternal and Child Health Bureau, and 15 Intellectual and Developmental Disability Research Centers funded by the National Institute for Child Health and Development. These programs are located in every state and territory and serve as a bridge between the university and community, working with people with disabilities, families, and communities to promote policy and practice. We would like to thank the commissioners for their work on the commission and their attention to long-term services and supports. We hope that our comments are helpful.

Our nation desperately needs a coherent national policy for long-term services and supports. Our recommendations rest on core beliefs: that everyone wants to live with or near the people they love, that everyone cares about the future of their loved ones, that getting older often means requiring some long-term services, and that everyone who cannot predict what tomorrow will bring should care about their own potential service needs. Despite these universal truths, information asymmetry, consumer confusion, lack of quality standards, and the failure of the private long-term care insurance market make LTSS access difficult, confusing, and almost impossible for most people. These problems pervade across state lines and affect the lives of every American. The current situation of LTSS in the United States is so fragmented and broken the term “system” carries inherent exaggeration. We look to you to create a national response to address this national problem.

To inform your work, we offer five recommendations. AUCD also supports the [Principles for Long-Term Services and Supports](#) jointly authored by the Leadership Council of Aging Organizations and the Consortium for Citizens with Disabilities and submitted to the commission. The

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recommendations below highlight our priorities as an organization committed to long-term services and supports policy that ensures inclusive participation, personal choice, personal responsibility, integration, and independence for people with developmental and other disabilities and their families.

- **Increase and expand supports to families providing caregiving:** Most people with developmental disabilities live at home with their families and most families receive little or no support. Providing support can improve outcomes for families and result in long-term savings.
- **Expand programs that allow access to supports without impoverishment so adults with disabilities can work and accumulate savings and assets:** Our current system requires most people to impoverish themselves and prove they cannot work in order to access long-term services and supports (LTSS). The commission should recommend expanding and enhancing programs that allow LTSS access for working adults and encourage savings and asset development.
- **Rebalance federally funded systems away from facility-based care toward home and community-based services and supports.** Medicaid LTSS still retains and entitlement to institutional care but optional home and community based services. Home and community based care should be available to all who need it, not after years on a waiting list.
- **Develop and promulgate LTSS quality measures, including measures on the direct support workforce.** Families need quality information to make good LTSS decisions and governments need quality data for accountability. The commission should recommend creation of national quality standards.
- **Create a national non-Medicaid social insurance program for long-term services and supports.** Medicaid was never designed to be our default long-term care social insurance program. The commission should recommend creating a program for this purpose.

We look forward to your report and thank you for your service on this important issue. Our full comments are included below.

Sincerely,

A handwritten signature in cursive script, reading "George Jesien".

George Jesien, PhD
Executive Director

Increase and expand supports to families providing caregiving

As the Commission heard in testimony from Dr. David Braddock, in 2011 72% of people with intellectual and developmental disabilities lived with family caregivers but only 13% of those families received support of any kind from the state. Dr. Braddock's testimony also showed that family support is currently declining in terms of state fiscal efforts. While many people want to remain with their families, family caregiving without support is unsustainable and often leads to more expensive and more restrictive placements.

Family support can range from intensive in-home caregivers to brief respite services. The commission should recommend increased funding for existing family support programs, including the National Family Caregiver Support Program, Lifespan Respite Care Program and family support programs authorized under Title II of the Developmental Disabilities Assistance and Bill of Rights Act that have never been funded by Congress. The commission should also recommend support an amendment to the Older Americans Act to provide supports to aging parents and siblings caring for their adult family members with developmental disabilities and an amendment to the Family and Medical Leave Act to expand the definition of "covered family member" to include siblings, grandparents, and domestic partners.

Expand programs that allow access to supports without impoverishment so adults with disabilities can work and accumulate savings and assets

People who are born with or acquire disabilities often have few choices but to impoverish themselves to access their required daily living supports through Medicaid. Few can afford to pay for services and their disabilities categorically exclude them from private coverage even if they could afford it. Too many people maintain poverty conditions in order to access LTSS, relying on Social Security and other benefits when they could be working, draining their productivity from the economy. Expanding access to personal attendant services and other LTSS for working adults will save money in other public benefits and help many people get back to where they want to be – at work. The commission should recommend expansions to the Medicaid Buy-In and similar programs that allow beneficiaries to work and develop assets while accessing LTSS.

Current legislation, known as the Achieve a Better Life Experience (ABLE) Act (H.R. 647 and S. 313) would also allow people with disabilities to develop tax-free savings and assets and move out of poverty conditions while retaining access to LTSS. The commission should include this legislation in its recommendations as a means of supporting savings and personal responsibility.

Rebalance federally funded systems away from facility-based care toward home and community-based services and supports

The current Medicaid program has a statutory entitlement to facility-based care, but services in the home or community remain optional. While some people may require advanced facility-based health care, most people who need typical daily living supports prefer home or community-based services. As a result, many states operate waiting lists for these optional home and community based services. The Kaiser Family Foundation reported that there were 511,174 people on official waiting lists for 1915(c) HCBS in 2011; 316,673 of them had intellectual and/or developmental disabilities.¹ The commission should recommend that home and community-based services be available to all who qualify without a waiting list. The commission could build upon the Community-First Choice Option, a state-plan option already available to states under section 1915(k) of the Social Security Act. This option provides an enhanced federal matching rate in exchange for access to home and community based services for all Medicaid beneficiaries who qualify for LTSS with no waiting lists.

Develop and promulgate LTSS quality measures, including measures on the direct support workforce

¹ Kaiser Family Foundation. "Waiting Lists for Medicaid Section 1915(c) Home and Community-Based Service (HCBS) Waivers" <http://kff.org/medicaid/state-indicator/waiting-lists-for-hcbs-waivers-2010/>

Despite its central role in the lives of people with disabilities, there are currently no national quality measures or standards for HCBS endorsed by either the federal government. People with disabilities and their families need information to make LTSS choices, including the quality of services available from LTSS providers.

The current proliferation of managed care in LTSS and demonstrations to integrate care for dually eligible beneficiaries provides an excellent opportunity to invest in outcome-oriented, person-centered quality measures. Not only does the move toward managed care increase families' need for information as providers are consolidated or changed, such measures are also required for accountability and payment of managed care organizations. The commission should recommend that CMS invest in developing national standards that build upon existing efforts. The AARP Scorecard,² National Core Indicators Project,³ Council on Quality and Leadership⁴ are examples of private efforts to measure person-centered outcomes on which the federal government could build.

Quality measures should also include information on the state of the direct support workforce. As the commission heard in testimony from Carol Regan, care services are difficult to find and often unreliable, hurried, inconsistent and lack important competencies and cultural sensitivities. We support Regan's recommendations on payment and procurement, training, coordinated care, and infrastructure to support independent living. We also urge the commission to include measures on direct support turnover, training, and availability in comprehensive LTSS quality measures.

Create a national non-Medicaid social insurance program for long-term services and supports.

Flaws in the current long-term care insurance market were well documented in the Commission's August 1 hearing, including unaffordability of private insurance, uncertainty that private policies will cover necessary costs when needed, misconceptions about what coverage Medicare and Medicaid will provide, and general misunderstanding of future LTSS needs. This market failure has made Medicaid our default national long-term care insurance program, a role it was never designed to handle. Medicaid is primarily a poverty program, providing health care to people who would not otherwise be able to afford it. But with limitations on access and high cost for private LTC insurance, Medicaid has become the only way for most people to access the supports essential to their daily living when they need them. We urge the commission to recommend a national non-Medicaid social insurance program to complement our safety net of supports provided through Medicare and Social Security to those unable to keep working because of old age or disability. Such a program can be actuarially sound, self-funded, and produce significant savings for Medicaid. We support the work of AdvanceCLASS, the National Council on Aging and other major aging and disability organizations who are advocating for such a program.

² www.longtermscorecard.org

³ <http://nationalcoreindicators.org>

⁴ www.thecouncil.org